

Seeking Treatment:

What? When? Why? Who? How? & Where?

In recent membership surveys, the National Association For Continence (NAFC) was distressed to learn that on average people were waiting years before seeking treatment for their bladder or bowel control problem. National research tells us that at least half of all Americans reporting symptoms of urine leakage or an overactive bladder have not consulted their doctor. This is hardly surprising when over two-thirds of all adult Americans have never discussed their urinary health with a health care professional.

NAFC has prepared this leaflet to help you explain your condition to a healthcare professional and to enable you to get the best and most economical results from your care.

Q. What is incontinence and what causes it?

A. Incontinence [in-CONT-ti-nunce], or loss of bladder or bowel control, is a symptom — not a disease in itself. A broad range of conditions and disorders can cause involuntary loss, including birth defects, pelvic surgery, injuries to the pelvic region or to the spinal cord, neurological diseases, multiple sclerosis, poliomyelitis, infection, and degenerative changes associated with aging. It can also occur as a result of pregnancy or childbirth.

Incontinence is a problem of the urinary system, which is composed of two kidneys, two ureters, a bladder, and a urethra. The kidneys remove waste products from the blood and continuously produce urine. The muscular, tube-like ureters move urine from the kidneys to the bladder, where it is stored until it flows out of the body through the tube-like urethra. A circular muscle called the sphincter controls the activity of the urethra. It is not a part of the urinary system but can play a role in incontinence.

Normally, the bladder stores the urine that is continually produced by the kidneys until it is convenient to urinate, but when any part of the urinary system malfunctions, incontinence can result.

Q. How common is incontinence?

A. According to the Clinical Practice Guidelines on Urinary Incontinence in Adults published in 1996 by the Agency for Health Care Policy and Research, 13 million Americans are

incontinent – 85% of them are women. More recent consumer research reveals that one in four women over the age of 18 experience episodes of leaking urine involuntarily. One in five adults over age 40 are affected by overactive bladder or recurrent symptoms of urgency and frequency, a portion of whom don't reach the toilet before losing urine. At least half of all nursing home residents are incontinent of urine and many of them experience loss of bowel control as well. In sum, the problem is widespread and affects people of all ages including children and young adults. NAFC estimates on the basis of multiple studies and expert opinion that 25 million adult Americans experience transient or chronic urinary incontinence.

Sufferers may experience emotional as well as physical discomfort. Many people affected by loss of bladder or bowel control isolate themselves for fear of ridicule and lose self-esteem. Adults may find employment impossible or compromised.

Q. What are the types of incontinence?

A. There are different types of incontinence:

- Stress incontinence occurs when sphincter or pelvic muscles have been damaged, causing the bladder to leak during exercise, coughing, sneezing, laughing, or any body movement that puts pressure on the bladder. A problem that commonly affects women, stress incontinence may occur after multiple childbirth or menopause. Pelvic fracture, radical prostatectomy, or bladder neck surgery can also damage the sphincter muscle and cause stress incontinence.
- **Urge incontinence**, the urgent need to pass urine and the inability to get to a toilet in time, occurs when nerve passages along the pathway from the bladder to the brain are damaged, causing a sudden bladder contraction that cannot be consciously inhibited. Stroke, dementia, Alzheimer's Disease, and Multiple Sclerosis (MS) can all cause urge incontinence.
- **Overactive Bladder (OAB)** includes symptoms of urinating more than eight times in a 24-hour period, a strong and sudden desire to urinate, and, if the urge cannot be controlled, urge urinary incontinence. An individual can have OAB and not be incontinent, but if an individual is diagnosed with urge incontinence, he has OAB.
- **Mixed incontinence** is very common and occurs when symptoms of both stress and urge types of incontinence are present. Symptoms of one type of incontinence may be more severe than the other. Treatment will depend on which symptom is more bothersome to the patient.
- **Overflow incontinence** refers to leakage that occurs when the quantity of urine produced exceeds the bladder's holding capacity. It can result from diabetes, pelvic trauma, extensive pelvic surgery, injuries to the spinal cord, shingles, MS, or polio.

Incontinence from surgery is a transient condition that follows such operations as hysterectomies, caesarean sections, prostatectomies, lower intestinal surgery, or rectal surgery. This is not considered a diagnostic category. Incontinence can also occur due to other reversible

factors, often outside of the urinary tract, such as restricted mobility. Mobility aids can help remove barriers to self-toileting on a timely basis. Other factors, such as arthritis, may interfere with managing zippers, buttons, and articles of clothing – or moving quickly enough to reach the toilet.

Q. When should I seek treatment for incontinence?

A. When you are not able to control your bladder or bowel as you once did or when the frequency or urgency to urinate is interfering with the quality of your life. Loss of bladder or bowel control could be the first symptom of something more serious; usually it is not. Many people change their lifestyle when their bladder or bowel habits begin to control their lifestyle. They may stop visiting friends, attending events, doing aerobics, enjoying intimacy, or traveling to see their children. You should seek treatment whenever changes in your bowel or bladder habits keep you from going and doing what you want to do.

Q. Why should I seek treatment for incontinence?

A. Because incontinence is a symptom potentially with many complex causes. Some causes are: infection, weakened pelvic floor muscles, low levels of female hormones, constipation, diabetes, prostate enlargement, multiple sclerosis, Parkinson's disease, and the effects of surgery. Other medical conditions or the effects of certain medications could also be the reason for your incontinence. When your incontinence is diagnosed and treated, often bladder and bowel control is greatly improved or completely restored. You should seek treatment to enjoy the happiest, healthiest, and most satisfying life possible.

Facts You Should Know

- **Incontinence** is the loss of bowel or bladder control.
- **Incontinence** — urinary and bowel — is believed to affect an estimated 25 million Americans.
- **Incontinence** affects people of all ages — young and old — both sexes, and people of all races.
- **Incontinence** is not a disease; it is not part of being a woman; and it is not what happens just as you get older.
- **Incontinence** is a symptom with different causes, so it is important to seek treatment to find out what is causing it and what can be done about it.

Q. Who should I see?

A. Your primary care provider (PCP) is the best place to start. This may be a physician, nurse practitioner, or physician's assistant. If your PCP does not have a special interest in diagnosing and treating incontinence, ask to be referred to a specialist.

Q. Who are the specialists who care for people with incontinence?

A. A **urologist** is a surgeon who specializes in the urinary conditions of men and women. Many urologists have advanced training in the surgical correction and medical treatments for incontinence; but not as many have experience with non-surgical treatments such as Kegel (pelvic muscle) exercises, bladder training, biofeedback, electrical stimulation, and the use of pelvic support devices or urethral inserts. A growing number of urologists are specializing in **female urology**.

A **gynecologist** is a doctor specializing in the reproductive health of women. Some focus on general gynecology and may serve as a woman's PCP. Others have special interest in the diagnosis and treatment of urinary incontinence and pelvic organ prolapse. If they have advanced training in this area, they may become **urogynecologists**.

A **geriatrician** is a doctor who specializes in treating older people. Some geriatricians have advanced training in the treatment and management of incontinence.

A **gastroenterologist** is a doctor who specializes in problems of the intestinal system. If you have diarrhea, constipation, or bowel incontinence, you may be referred to a gastroenterologist. Some specialize in surgery and are known as **colorectal surgeons**.

Some **nurse specialists, psychologists, physical and occupational therapists, and behavioral scientists** have training that qualifies them to offer non-surgical treatments for incontinence. This is true in the case of electrical stimulation and biofeedback therapy as a means of behavioral treatment.

There are several ways to find the right specialist. Begin by asking your family doctor or PCP for a referral to an incontinence specialist. By visiting our Web site, www.nafc.org, or by calling us at 1-800-BLADDER, we can provide a listing of the specialists in your area who have qualified for affiliation in NAFC's growing Continence Resource Service (CRS). If we do not list a healthcare professional within driving distance of your home, you may want to look in your local yellow pages directory where physicians are listed. Call your local hospital and ask if the hospital has a continence clinic as part of its women's health center or OB/GYN Department. Confide in a friend. Often friends will tell you where they had their treatment and if they were satisfied.

When you are looking for a qualified specialist for yourself or someone you care for, ask the following questions before you make an appointment. Unless the receptionist answers “yes” to at least eight of the ten questions, you should call another specialist.

- Does the specialist have a particular interest and training in the diagnosis and management of incontinence problems?
- Does the specialist have the ability to do special office testing of bladder function to help determine the cause of incontinence?
- Do other health professionals refer incontinent patients to this specialist?
- Does the specialist have experience in the treatment of patients who have had previous unsuccessful attempts at correcting their incontinence?
- Is the specialist experienced with non-surgical forms of treatment for incontinence, such as pelvic muscle exercises, behavioral therapy, intermittent self-catheterization, etc.?
- Does the specialist teach other health professionals about the diagnosis and treatment of incontinence?
- Is the specialist experienced in the evaluation of patients for the implantation of the artificial urinary sphincter?
- Is the specialist experienced in the evaluation and treatment of incontinence related to birth defects, such as spina bifida, and accidents that cause spinal injury or bladder damage?
- If my incontinence cannot be cured, can the specialist or someone in the office direct me to printed information, support groups, web site addresses and/or management alternatives that will help?
- Does the specialist know about the Agency for Health Care Research and Quality (AHRQ), Clinical Practice Guideline for the Treatment of Urinary Incontinence in Adults and about the National Association For Continence (NAFC)? Is the specialist a member of NAFC?

Q. How should I prepare for my appointment?

A. #1 — Be ready to answer these and many other questions that will be asked of you. This is called a “Medical History.”

- How often do you urinate (“pass your water”) each day? *
- How much liquid do you drink each day? How much with meals or between meals? *
- Do you leak urine when you cough or exercise?
- Do you feel a sudden urge to urinate? *
- Do you have to rush to the toilet?
- Do you sometimes not make it?

- Do you have trouble starting your urine stream?
- Is your urine stream like it always has been, or does it seem “slow” or “weak”?
- Do you feel like you empty your bladder?
- Do you have to strain or push?
- Do you dribble or leak urine after you think you have finished urinating?
- How many times do you get up at night to use the toilet? *
- Does it ever hurt or burn when you urinate?
- Does your urine have a bad odor or appear dark yellow or “strong”?
- Do you ever see blood in your urine?
- When did this problem of leakage start?
- How often do you wet your clothing? *
- How many pads do you wear each day? Are they wet when you change them?
- Are there a few drops in the pad, or a bladder full? *
- How often do you have a bowel movement?
- Are your stools soft, soft and formed, hard, easy to pass, difficult to pass?

The questions marked with an * will be answered if you keep a bladder diary (Uro-Log) for at least two days before your appointment (see enclosure). On this diary, record each time you urinate, how much urine you pass, what you drink and eat each day, when and how much leakage you have, and what you were doing when the leakage occurred.

#2 — Take a list of all your doctors and medical conditions, such as diabetes, high blood pressure, etc. to your appointment.

#3 — Take a list of any operations you have had and when you had them. Women should list the number of pregnancies, number of deliveries, weight of their babies and whether they were delivered through the vagina or by Caesarean section. Also reveal information about recurring urinary tract infections or chronic pelvic pain.

#4 — Show the doctor all your medicines. We suggest you get three food-storage size bags. In one, put all the prescription medicines you are taking that have been prescribed or refilled during the last 30 days. In the second bag, put all the prescriptions that you keep in the house but that you don’t take regularly. In the third, put all the over-the-counter medicines, vitamins, and cold remedies that you take.

#5 — Be prepared to describe how incontinence affects your daily life. Make a list of the most bothersome problems related to your incontinence.

#6 — Explain any skin inflammation or irritations you suffer from because of urine or fecal leakage.

#7 — On the day of your appointment, expect to be asked for a urine specimen. Talk with the doctor's receptionist when you make the appointment and when you arrive to see if there are tests or preparations for tests that you should know about.

Q. What should I expect when I seek treatment?

A. Expect the health professional to be concerned about your complaint and to be attentive to the information you bring. Be ready to give a complete history, which will include the questions we have listed for you and probably many more. Expect to have a complete physical examination. You will be asked to give a urine specimen, and you should be tested within 15 minutes after that to see if there is still urine in the bladder. Sometimes this is done by passing a small thin tube (catheter) into your bladder. Other times it is done with a small sensor that is rubbed over your lower abdomen. This is called an ultrasound. A sample of your blood may also be taken.

The doctor may begin treatment immediately or do some other tests called urodynamics [**y**er-o-die-NAM-icks]. These tests show how your bladder acts when it is filling and emptying. The reason for all tests should be explained, and you should know when, how, and where you will get the results.

Once the specialist has made a diagnosis of your bladder or bowel problem, you should expect to have the treatment choices explained to you with the risks and benefits and estimated cost of each.

And finally, expect to participate in your care to get the best results. Your treatment will be most successful when you help choose the solution and when you do all that you need to do in the way of record-keeping, going to the toilet regularly, drinking the recommended amount and type of fluids, and performing exercises if you are told to do so. Of course, you should report any side effects of medicines or treatments and discuss any concerns you have about your treatment with your PCP or health care professional.

Q. What treatments will help my condition?

A. Behavioral therapies, medicine, surgery, and absorbent products and devices are options recommended by the **Clinical Practice Guideline for Urinary Incontinence in Adults**. This

Guideline, released in 1992 and updated in 1996 by the Agency for Health Care Research and Quality of the U.S. Public Health Service, was developed by a panel of experts invited by the government to study the problems of incontinence and to make recommendations for treatment. Some types of incontinence have more than one treatment option. Discuss the options for your type of incontinence with your physician and your family, and choose the one that is best for your lifestyle.

Q. What should I expect to happen after I receive treatment?

A. You probably should not expect your incontinence to go away in a day or two if you have had it for a long time. Have your healthcare specialist explain the results you should expect. You should know whether to expect your condition to improve in a matter of days, weeks, or months. Be watchful for changes and improvements, however small.

Q. Should I expect to be cured?

A. In many cases, yes. In most cases, incontinence can be cured or significantly improved. If you have a condition, such as multiple sclerosis or spinal cord injury, you may not be able to change your incontinence; but you should be able to manage it comfortably without the embarrassment of leakage or odor.

Q. What about incontinence and skin care products?

A. They are very important for your comfort and confidence. Use of the proper products will protect your skin from irritation and will protect you and your home from embarrassing odor. Along with the Quality Care quarterly newsletter and access to the Continence Resource Service, NAFC Members receive a complimentary copy of the **Resource Guide® — Products and Services for Incontinence** (membership — \$25 annually). All incontinence products are illustrated, described, and cross-referenced to their manufacturers. The **Resource Guide®**, which is updated annually, is available to non-members by sending \$15 (postpaid) to, NAFC, P.O. Box 1019, Charleston, SC 29402.

Q. Where can I receive more information about incontinence?

A. The following items are available through the National Association For Continence. To order, you may send a check to NAFC, PO Box 1019, Charleston, SC 29402, or order with MasterCard or VISA by calling 1-800-BLADDER or visiting www.nafc.org.

■ **Your Personal Guide for Bladder Health** – This 48-page booklet encompasses a wide variety of topics. Perfect for patients, caregivers, and health professionals alike, its essay-like

format explains complex issues in simple terms. (\$8.95 postpaid)

■ **Pelvic Muscle Exercises for Men** – This audiocassette tape is most helpful for men experiencing urine leakage after prostate surgery. The accompanying training manual helps you to follow the verbal instructions with written descriptions and detailed drawings. (\$6.00 postpaid)

■ **Women's Pelvic Muscle Exercises Instruction Kit** - This kit is most helpful for women with mild to moderate stress incontinence and overactive bladder. It includes a manual with descriptions and detailed drawings, a motivational video and instructional audio recording. Select DVD/CD or VHS/Cassette. (\$15.00 postpaid)

Questions You Should Ask:

About prescriptions

- Why do I need this medication?
- What are typical side effects?
- How soon should my symptoms improve?
- Are there any special instructions?
- What drug interactions might occur?

About tests

- What will this test show you?
- How accurate is it?
- How will it affect my treatment?
- Are there any risks or side effects?
- Do I need to do anything special before or after the test?
- How much will it cost?

About treatment and surgery

- What are the benefits and risks?
- How soon will it improve my condition?
- Are other treatments available?

- Can you refer me to another physician for a second opinion?
- If surgery is needed, how long will I be hospitalized and what will it cost?
- Can it be done as an outpatient procedure?
- What is the average recovery time?

10 Warning Signs of Bladder Problems

See Your Health Care Provider If You Are Experiencing:

1. Leakage of urine which prevents activities.
2. Leakage of urine, causing embarrassment.
3. Leakage of urine which began or continued after an operation (hysterectomy, caesarean section, prostate surgery, etc.).
4. Inability to urinate (retention of urine).
5. Urinating more frequently than usual without a proven bladder infection.
6. Needing to rush to the bathroom and/or losing urine if you do not “arrive in time.”
7. Pain related to filling the bladder and/or pain related to urination (in the absence of a bladder infection).
8. Frequent bladder infections.
9. Progressive weakness of the urinary stream with or without a feeling of incomplete bladder emptying.
10. Abnormal urination or changes in urination related to a nervous system abnormality (stroke, spinal cord injury, MS, etc.)